

Massachusetts

Developmental

Disabilities

Council

FFY 1999 ANNUAL PROGRAM
PERFORMANCE REPORT



*174 Portland Street
Boston, MA 02114
(617)727-6374 (Voice)
(617) 727-1885 (TTY)
(617) 727-1174 (FAX)
email: council@mddc.state.ma.us*

I: INTRODUCTION

The mission of the Massachusetts Developmental Disabilities Council is to provide opportunities for people with developmental disabilities and their families to enhance independence, productivity, integration and inclusion.

The Massachusetts Developmental Disabilities Council is comprised of twenty-eight volunteer members and a small staff. Members are appointed by the Governor for up to three-year terms, and include individuals with developmental disabilities, family members or guardians of people with developmental disabilities, professionals, advocates, and representatives of state and private service agencies. It is the Council's belief that the greatest impact on public policy occurs through self-advocacy, which is supported by the development and maintenance of strong coalitions. We work to educate policy makers by bringing people with developmental disabilities and their families together with policy makers to advocate on their own behalf. The Council fosters and supports coalitions with other advocacy and community groups, and supports close working relationships among and between the various public and private service providers.

Although the exact number is unknown, it is estimated that over 108,000 Massachusetts citizens have a developmental disability. A "developmental disability," as defined in federal law, is a severe, chronic, often lifelong disability that causes substantial limitations in several major life activities such as: self care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, and economic self-sufficiency. It is attributable to a mental, emotional, sensory, and/or physical impairment that is apparent before the age of twenty-two. People with developmental disabilities often need a combination of special services, supports, and other assistance that is likely to continue indefinitely. People with developmental disabilities constitute the most severely underserved population in the Commonwealth.

The Council develops Annual State Plan objectives to address the most important issues affecting people with developmental disabilities. Priorities are established through the input from people with developmental disabilities and their families. Initiative teams, which include members and staff as well as consumers, advocates, and other interested individuals, develop both short and long-term objectives and action plans to address these priorities. The Council's success is measured by both its ability to achieve the outcomes established by the State Plan, and the real impact that these outcomes have on the lives of people with developmental disabilities and their families.

1999 was the second full year in which Councils were required to report the quantitative results of their activities. The results

identified in this report were generated from both the activities undertaken to meet the Council's State Plan Objectives and through collaborative activities undertaken with our DD Partners, the University Affiliated Programs and the Protection and Advocacy Agency, as well as our partnerships with other state agencies and the disability advocacy community.

II: REPORTING YEAR STATE TRENDS

The impact of the Olmstead case was immediately evident in Massachusetts as two major lawsuits were filed in 1999. In *Rolland v. Cellucci* was filed on behalf of 1600 nursing home residents with developmental disabilities not receiving medically necessary services in the most integrated settings. Plaintiffs argued that these class members were unnecessarily admitted to and inappropriately confined to nursing facilities, and could live in the community if provided with appropriate supports medical services. A settlement agreement provides that 75 individuals will receive residential and other supports in SFY 2000, another 175 in 2001 and 2002, and 150 per year from 2003-2007. Specialized services will also be provided to members residing in nursing homes. The state legislature added \$2 Million in additional resources to the DMR Waiting List account to provide services for nursing home residents with developmental disabilities in 2000.

Anderson v. Cellucci focuses on the 2400 people on the DMR waiting list. Plaintiffs argue that the Medicaid Act requires services to be provided in a "reasonably prompt manner". The suit seeks to offer all plaintiffs the full range of ICF/MR or home and community based waiver services within 90 days, all eligible plaintiffs the choice of receiving ICF/MR or home and community based services, and a fair hearing to plaintiffs not provided Medicaid services within 90 days.

Increases in funding for disability programs continued in 1999. The DMR received a \$10 million increase to provide services for people on the waiting list. It is estimated that 443 people will receive services, 143 of who are currently in crisis situations. As a direct result of the advocacy efforts of the Council supported Disability Policy Consortium (DPC), funding for three historically neglected agencies increased by \$8.5Million. MRC received \$7 Million for vocational rehabilitation, employment assistance, independent living, home care and head injury services. The Commission for the Deaf and Hard of Hearing received \$112,501 for interpreter services and operations, and the Commission for the Blind received \$1.388 Million for turning 22, vocational rehabilitation, workshop services, Medicare and administration.

The Senior Pharmacy Program received a \$21.7 Million increase that raised the maximum income eligibility requirement and increased the annual benefit up to \$1,250 per year. \$20 Million was also appropriated for a new Pharmacy Plus, Catastrophic Pharmacy Assistance Program for elders and younger persons with disabilities experiencing high prescription expenses. The state also initiated a program to aggregate the purchase of prescription drugs to make pharmacy costs more affordable to the Senior Pharmacy and Pharmacy Plus recipients, among others.

The new Home Modifications Loan Program was financed through a bond providing \$10Million over five years. MRC received \$2 Million in 1999 and has begun implementation of the program. People have enrolled in a lottery for the first round of deferred payment loans from \$1,000 to \$25,000, which will be made available at 0% interest or below market rate depending on income. MRC estimates that 200 eligible households per year will be served under this program.

III. COUNCIL RESULTS

Self-Determination

The MDDC Consumer Empowerment Program provides opportunities for people with DD and family members to attend conferences, training sessions and similar events to enhance their self-advocacy and leadership skills. Through a grant to Regina Villa Associates the Council conducted legislative advocacy training and assisted low-incidence disability groups to develop advocacy strategies to promote their legislative agendas. The Council also continued support to the advocacy efforts of the Disability Policy Consortium. The Council held its bi-annual orientation for new legislators and annual Legislative Reception to continue efforts to bring people with DD together with policymakers to advocate on their own behalf. The Council also conducted a statewide campaign to raise public awareness of the contributions of persons with developmental disabilities. The MDDC awarded several small grants under self-determination. MA Advocates Standing Strong, a new organization led by self-advocates to support smaller groups across the state, held its founding conference. MA Families Organizing for Change strengthened individual and family advocacy in the Boston Metro Region, the Neal Pike Institute updated and disseminated an Estate Planning Guide, and The Boston Foundation and the Disability Law Center implemented the "Leadership Opportunities for Youth with Disabilities" project. The Council published "People First", an analysis of all budget line items relevant to the disability community. The MDDC participated in a joint initiative with NCSL to facilitate communication with its members to better impact state policy on DD. The Council continued its collaboration with other disability groups, including the SILC, the Coalition for the Legal Rights of Persons with Disabilities, the Governor's Commission on MR, the DMR Statewide Advisory Council and the Governor's Interagency Coordinating Council.

951people have control, choice and flexibility in the services/supports they receive

403 people on waiting list(s) received services/supports

\$46,228,858 public dollars were leveraged for person-directed individual services/supports \$10,676,351public dollars were leveraged for family-directed family services/supports

\$193,225 private dollars were leveraged for individual- and family-directed services/supports \$12,600 dollars were leveraged to expand Council self-determination projects \$63,488 dollars were leveraged to expand Council family services/supports projects

18 people attained membership on public and private bodies and boards

75 people in generic occupations received training in person-and family-directed services/supports 262 public policymakers were educated about person-and family-directed services/supports 2,358 copies of products were distributed to policymakers about services/supports

517 people were active in systems advocacy about person-and family-directed services/supports 980 people were trained in systems advocacy about person- and family-directed services/supports

3,549 members of the general public were reached through Council public awareness activities

149 people were supported through the Council's Consumer Empowerment Funds (CEF) Program

Employment

The MDDC continued to support the Disability Employment Project, a multiyear collaborative between the Council, MRC and the state Human Resources Division and the Council to provide employment opportunities for people with severe disabilities in state government. In collaboration with the Northeast Independent Living Program, the Council conducted an assessment study to analyze career development programs for students between the ages of 12-18. The project identifies programs that provide optimal inclusion and choice for students and works to replicate successful strategies in additional districts. The Council conducted a statewide campaign to raise public awareness of the contributions of persons with DD to their communities and to improve employment opportunities. This initiative was implemented in partnership with the Departments of Mental Retardation and Rehabilitation, and the Governor's Commission on Employment. The MDDC awarded several small grants under employment. Seven Hills Occupational & Rehabilitation Services provided education in self-determination and work based learning experiences, to prepare students with developmental disabilities for employment. The Council also provided funding for mini-grants to minority organizations through the Institute for Community Inclusion. The Capacity Interchange Project increases the capacity of grassroots minority and diverse organizations to develop and enhance supports and services for individuals and families. The Council continued its collaboration with other disability groups through active participation on numerous work groups and task forces. These organizations include the MA Partnership for Transition, the MA Transition Initiative, the President's Committee for the Employment of People with Disabilities, the Business Leadership Network Committee, the Employment Services Action Council, the

Statewide Independent Living Council, and the Rehabilitation Advisory Committee.

21 Adults have jobs of their choice

\$4,925,107 public dollars were leveraged for employment programs

131 people on waiting list(s) received services/supports

\$213,103 dollars were leveraged to expand Council employment projects

7 employers provided vocational supports to students on the job

18 businesses/employers employed adults

1 new public employment program/policy was created

5 current public employment programs/policies were improved

52 people in generic occupations/professions facilitated employment

182 people in disability-related occupations/professions facilitated employment

658 public policymakers were educated about employment

190,170 members of the general public were reached by Council public awareness activities

Housing

The MDDC successfully advocated for the release of \$10 million in bond funds for the Home Modification Loan Program. The program provides loans at 0% interest or below market rate, depending on income, to people with disabilities requiring access modifications. The Massachusetts Rehabilitation Commission will administer the Program in conjunction with the Community Economic Development Assistance Corporation (CEDAC), a quasi-public agency experienced in working with bond funds and housing programs for people with disabilities. MRC estimates that it will serve about 200 households per year. The Council awarded a grant to Arc Massachusetts to provide statewide housing seminars to educate people with developmental disabilities and their family members about housing opportunities in Massachusetts. The Arc will connect to 2000 people through extensive outreach to local communities. Support centers will provide multiple training sessions, connect people to the appropriate housing resources and provide ongoing support as needed. A grant was awarded to Citizen's Housing and Planning Association to conduct trainings to increase self-determined housing and supports among people with developmental disabilities. Five regional trainings were conducted in collaboration with the Home of Your Own Alliance, presenting successful approaches to housing and supports. A homeownership resource guide for people with disabilities was also produced. The Council continued its collaboration with other disability groups through active participation on numerous housing work groups and task forces. These organizations include the Advisory Committee to the Massachusetts Rehabilitation Commission for the Home Modification Loan Program, the Boston Housing Authority Consolidated Plan Disability Advisory Group, and the Disability Law Center housing forum.

7 individuals have homes of their choice through a Council demonstration project

125 people on waiting list(s) received services/supports

163 people moved from congregate settings to homes in the community

\$2,000,000 public dollars were leveraged for housing

\$32,707 dollars were leveraged to expand Council housing projects

200 units of affordable, accessible housing were made available

60 people in generic occupations/professions received training in housing

155 people in disability related occupations/professions received training in housing

356 public policymakers were educated about housing

5,240 copies of products were distributed to policymakers about housing

22 people were active in systems advocacy about housing

965 people were trained in systems advocacy about housing

6,000 members of the general public were reached through Council public awareness activities

1,500 copies of the Housing Options publication were distributed to individuals and families

Health

The Council collaborated with the Department of Public Health and New England Index to expand the database of physicians serving people with disabilities to include dentists. Developed by New England Index, the database is a computerized network of information available through independent living centers, the Council and many other organizations. A hard copy resource book, identifying dentists across the state with experience serving people with DD is also under development. The MDDC is working with faculty at Tufts Dental School to develop curriculum for training dentists on effectively treating people with DD. The project includes a symposium lead by dental educators, clinicians and persons with DD, and development of comprehensive didactic curriculum in a flexible format for use in dental schools and continuing education programs for practicing professionals. Tufts Dental School has made a commitment to incorporate the didactic curriculum and to develop a clinical component to provide students with practical experience, and access to care at Tufts University dental clinics to people with DD. The MDDC awarded several small grants under health. Medicaid Working Group updated and revised a managed care curriculum and conducted statewide trainings about managed care programs for people with DD, to enable them to advocate for programs that meet their needs. The Association for Community Living conducted trainings to support coordinated health services between hospital and home settings. Boston Self-Help Center produced and disseminated a video on Multiple Chemical Sensitivity. The Council continued its collaboration with other disability groups through active participation on numerous work groups and task forces. These organizations include Health Care for All, the Statewide Personal Assistance Coalition, the Dental Registry Advisory Group, and the Universal Health Care Action Network.

3,578 people have needed health services

\$6,879,783 public dollars were leveraged for health services

\$10,341dollars were leveraged to expand Council health services projects

\$3,110,635 public dollars were leveraged for prevention

2 new public health care programs/policies were created

2 current public health care programs/policies were improved

2 prevention programs/policies were created/improved

82 people in disability related occupations/professions received training in health care

31 people were involved in systems advocacy on health care

180 people were trained in systems advocacy about health care

272 members of the general public were reached through Council public awareness activities

1 Information and referral service for access to dental services for people with developmental disabilities was established through New England Index

Education

In collaboration with the Federation for Children with Special Needs the MDDC conducted information and training sessions to families of Portuguese children with developmental disabilities about their children's educational rights. This project translated into Portuguese and printed two thousand copies of the Chapter 766 brochure and a Parent Manual, which were used in Basic Rights Workshops and Parent Consultant Training Programs for parents of children with DD. Eighty Portuguese families attended Basic Rights Workshops and fifteen Portuguese families participated in the Parent Consultant Training through which five families received support and assistance to advocate for the rights of their children. In addition forty families with children with DD received additional support and information. The project has increased awareness in the Portuguese community and has effectively addressed many educational needs of this underserved community.

The Council actively participates on the Early Intervention Interagency Coordinating Council (EIICC). The EIICC is the statewide interagency group that advises and assists the Massachusetts Department of Public Health in the planning, development, implementation, and oversight of the early intervention service system. It represents the interests of children at risk for or with developmental delay and their families and monitors state compliance, promotes information sharing, interagency coordination, and collaboration. The ICC has led the shift from center-based care to child group services in natural environments, disseminated brochures on the needs of children with low incidence disabilities (blindness, autism, and PDD), and developed a physician's guide to EI program referrals.

2,425 infants and young children have the services/supports needed to

reach developmental goals

\$995,840 public dollars were leveraged for education

\$5,000 dollars were leveraged to expand Council inclusive education projects

9 people in disability related occupations/professions received training in inclusive education

2 public policymakers were educated about inclusive education

200 copies of products were distributed to policymakers about inclusive education

18 people were involved in systems advocacy about inclusive education

45 parents were trained regarding their child's educational rights

400 members of the general public were reached by Council public awareness activities

2,000 Chapter 766 brochures and parent training manuals were translated and disseminated to Portuguese families

Community Inclusion

The Council Team on Supports to Aging Caregivers completed a report on the needs of elder caregivers and provided recommendations for changing the system in Massachusetts to better meet these needs. The Team met with key staff from the Department of Mental Retardation and the Executive Office of Elder Affairs to promote coordination around supporting the needs of elder caregivers and aging individuals with developmental disabilities. The Council successfully negotiated an Inter-agency Service Agreement to initiate collaborative activities, including surveys and focus groups of elder serving staff, DMR care coordinators, family support providers, and elder caregivers, cross-trainings and pilot projects designed to improve coordination of services.

The Council supported a project by the Massachusetts Brain Injury Association to recruit and match college student volunteers with brain injury survivors for one on one and group social activities. The project organized seven college campus PALS Chapters in the Worcester, MA Area having an on going, self-sustaining potential. PALS recruited and trained fifty-eight student volunteers on brain injury and its effects. The project screened thirty brain injury survivors and matched them each with two College PALS (student volunteers). Through weekly phone and e-mail correspondence and events that included movie nights, bowling, going to the mall and the science museum with their

College PALS, brain injury survivors were able to make new friends and regain their self-esteem.

15 individuals are valued, participating members of their communities through Council projects

700 people on waiting list(s) received services/supports

\$307,500 public dollars were leveraged for transportation

\$6,600 dollars were leveraged to expand Council community inclusion and participation projects

7 private organizations programs/policies became more inclusive

10 people in generic occupations facilitated community inclusion and participation

98 people in generic occupations received training in community inclusion and participation

86 people were trained in systems advocacy about community inclusion and participation

232 members of the general public were reached by Council public education, awareness and media initiatives about community inclusion and participation

IV: REPORTING YEAR EXPENDITURES

A. Types of Recipient

RECIPIENT	Part B \$	Match \$	TOTAL
1. DD Council	\$568,272	\$82,924	\$651,196
2. Designated State Agency	\$50,000	\$55,600	\$105,600
3. Other(s) State Agency	\$63,600	\$21,700	\$85,300
4 P & A System	\$5,000	\$105,000	\$110,000
5. UAP	\$0	\$0	\$0
6. Non-Profit Organizations	\$393,512	\$313,874	\$707,386
7. Other	\$27,283	\$0	\$27,283
8. TOTAL	\$1,107,667	\$579,098	\$1,686,765

B. Cost Categories - Priority Areas, General and DSA Functions

CATEGORY	Part B \$	Other(s) \$	TOTAL
1. Employment	\$203,316	\$199,184	\$402,500
2. Child Development	\$0	\$0	\$0
3. Community Living	\$133,149	\$0	\$133,149
4. System Coordination	\$430,416	\$225,684	\$656,100
5. State Priority: Health Care	\$61,795	\$15,706	\$77,501
6. General Management	\$228,990	\$82,924	\$311,914
7. Functions of the DSA	\$50,000	\$55,600	\$105,600
8. TOTAL	\$1,107,667	\$579,098	\$1,686,765